



July 9, 2004

Ms. Mame Templeton  
White House Conference on Aging  
Administration on Aging  
Department of Health and Human Services  
Washington, DC 20201

Dear Ms. Templeton:

On behalf of the Alzheimer's Foundation of America (AFA) and its member organizations, thank you for the opportunity to offer our suggestions regarding priorities for the 2005 White House Conference on Aging for consideration by members of the Policy Committee at its meeting on July 14, 2004.

### **Summary of Comments**

We want to highlight for Committee members an important initiative launched by AFA to promote memory screening with the goal of early diagnosis of Alzheimer's disease and related dementias. AFA has developed a legislative proposal to expand access to memory screening on a nationwide basis through a public-private partnership with the federal government, and we would welcome the Policy Committee's support for that effort.

### **The Foundation's Mission**

The Alzheimer's Foundation of America (AFA) is a nonprofit 501(c)(3) organization founded to fill a gap that existed on the national front for advocacy of "care...in addition to cure" for individuals affected by Alzheimer's disease and related dementias. AFA is dedicated to meeting the educational, social, emotional and practical needs of individuals with Alzheimer's disease and related illnesses, and their caregivers and families.

AFA's members are grassroots organizations that offer direct, "hands-on" services such as respite care, support groups, cognitive therapy programs, educational workshops, and memory screening for individuals with the disease and their families. Our goals include improving quality of life for all those affected and raising standards for quality of care.

In addition, AFA operates a national resource and referral network with a toll-free hotline, develops and replicates cutting-edge programs, hosts educational conferences and training for caregivers and professionals, provides grants to member organizations for hands-on support services in their local areas, and advocates for funding for social services. It annually sponsors two national initiatives, National Memory Screening Day and National Commemorative Candle Lighting.

Founded in February 2002, AFA now represents organizations in nearly all 50 states. AFA has also established collaborative partnerships with other national groups, including The Leeza Gibbons Memory Foundation, Project Lifesaver and Sunrise Senior Living.

## **The Importance of Memory Screening**

AFA launched National Memory Screening Day in 2003 as a collaborative effort by organizations and health care professionals across the country to promote awareness and early detection of memory impairments. AFA initiated this effort in direct response to breakthroughs in Alzheimer's research that show the benefits of early intervention for individuals with Alzheimer's disease, as well as the benefits of counseling and other support services for their caregivers.

AFA's National Memory Screening Day underscores the importance of early diagnosis, so that individuals can obtain proper medical treatment, social services and other resources related to their condition. With no cure currently available for Alzheimer's disease, it is essential to provide individuals with these types of interventions that can improve their quality of life while suffering with the disease.

During National Memory Screening Day, healthcare professionals administer free memory screenings at hundreds of sites throughout the United States. A memory screening is used as an indicator of whether a person might benefit from more extensive testing to determine whether a memory and/or cognitive impairment may exist. While a memory screening is helpful in identifying people who can benefit from medical attention, it is not used to diagnose any illness and in no way replaces examination by a qualified physician.

The benefits of an early diagnosis of a memory disorder are enormous. Early diagnosis can go a long way toward improving quality of life. National Memory Screening Day represents a giant step toward leading individuals up the right path.

Our goal is for individuals to follow up with the next steps—further medical testing and consultation with a physician, if the testing raises concerns. The latest research shows that available and emerging treatments can slow the symptoms of Alzheimer's disease and that individuals begin to benefit most when they are taken in the early stages of memory disorder. This intervention may extend the time that individuals can be cared for at home, thereby dramatically reducing the costs of institutional care.

With early diagnosis, individuals with the disease and their families can also take advantage of support services, such as those offered by AFA member organizations, which can lighten the burden of the disease. According to several research studies, such care and support can reduce caregiver depression and other health problems, and delay institutionalization of their loved one—again reducing the economic burden of this disease on society.

In addition, with early diagnosis, individuals can participate in their care by letting family members and caregivers know their wishes. Thus, memory screenings are an important tool to empower people with knowledge and support. Just as importantly, the screenings should help allay fears of those who do not have a problem as well as provide them with information about cognitive wellness intervention.

AFA holds National Memory Screening Day on the third Tuesday of November in recognition of National Alzheimer's Disease Month. TV and radio personality Leeza Gibbons serves as the national advocate for this initiative. Ms. Gibbons founded The Leeza Gibbons Memory Foundation in response to

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her own family's trial with Alzheimer's. She lost her grandmother to the disease, and her mother now battles with the final stages of Alzheimer's.

This year, National Memory Screening Day will be held on November 16, 2004. Individuals concerned about memory problems will be able to take advantage of free, confidential screenings at hundreds of sites across the country with the goal of early diagnosis of Alzheimer's disease or related dementias. Early diagnosis is critical, because as Ms. Gibbons has noted, "This is not a disease that will wait for you to be ready."

### **The Need for Federal Leadership**

As promising research continues in the search for a cure, additional resources are also needed in support of efforts to delay the progression of Alzheimer's disease and related dementias. The federal government can play a critical role in that regard by providing resources for a public health campaign designed to increase awareness of the importance of memory screening and to promote screening initiatives.

Federal support is essential to expand the scope of ongoing efforts in the private sector. Working in partnership with AFA and other participating organizations, the federal government can leverage its resources cost-effectively to help overcome fear and misunderstanding about Alzheimer's disease and related dementias, to promote public awareness of the importance of memory screening, to expand options for screening nationwide, and to direct Americans to the support services and care available in their local communities.

AFA therefore recommends the passage of legislation to authorize the Secretary of Health and Human Services to provide support for the development, expansion, and operation of programs to promote public education and awareness regarding the importance of memory screening and to expand access to screening services for memory impairment nationwide. This initiative represents a simple, cost-effective intervention that would benefit persons with Alzheimer's disease by prompting them to seek early diagnosis and treatment, while providing reassurance and information about cognitive wellness intervention to the majority of individuals who do not show signs of memory impairment.

AFA appreciates the Committee's leadership on aging issues and welcomes the opportunity to work together to improve the quality of life for those with Alzheimer's disease, their caregivers and family members. Please feel free to contact me at 866-232-8484 or Todd Tuten at 202-457-5215 if you have questions or would like more information.

Sincerely,



Eric J. Hall  
Chief Executive Officer